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PRESENT:
Stephanie Aaronson
Donna Appell, R.N.
John T. Burklow, M.S.
Lora M. Church
Gardiner Lapham, M.P.H., R.N.
Amye Leong, M.B.A.
Jordan P. Lewis, M.S.W.
Eileen Naughton, J.D.
Gregory R. Nycz
Lynn M. Olson, Ph.D.
Carlos Pavão, M.P.A.
Lawrence Tabak, D.D.S., Ph.D.
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WELCOME

MR. PAVAO: Welcome, everyone.

Thank you very much, Dr. Tabak, for being here today.

We have a very, very good presentation for you that's going to tie in from last time to today and the work that we've done but before we actually dive into the work we wanted to spend a couple of minutes if we go around just briefly, state our names and where we're from, what state you're from, and also just talk about any observations that you've noticed when it comes to biomedical and behavioral research lately in your communities that you think that NIH needs to hear about.

So with that said I want to turn to Lynn.

INTRODUCTIONS

DR. OLSON: So thank you. I am Lynn Olson. I am the Director of Research at the American Academy of Pediatrics and so live in the Chicago area. I guess the observation I would make are a couple of very recent things.

One was just last week. It was the closure of comments on the advanced notice of changes to the Common Rule and to my mind related to that was an IOM report,

workshop report that came out last week on public engagement in clinical trials.

And what these both represent to me is an ongoing indication of a need for public engagement in research and for public engagement in understanding what it means for people to participate in research but what I was struck with in both of these things is that there is really such a lack of what I call research on research. In other words, you know, there's--in both of these a lot of experts and good thinking people trying to think about how can we better engage, how can we make consent better, how can we engage but a lot of it is experts talking to each other.

We really have very little data from people themselves. Why or why don't you participate in trials? What does it mean to you once you have? How do you understand the consent process? What about these new issues related to biological samples and using them over time? We really have very little information on how people really feel on these things and it's kind of remarkable, you know, in the big scientific enterprise we have how little information there is on these key points from the participant's point of view.

There were 1,000 comments I think on the Common Rule changes. I think a lot is going to be said and I think a lot will have to do with we don't really know how participants themselves think.

So I just thought those were really great examples of the important need for continuing to understand the public perception.

MS. NAUGHTON: I'm Eileen Naughton. I'm from Rhode Island, the smallest state in the union.

And I think it's important to let you know that my husband is a dentist and he very much likes the fact that you're deputy director.

One of the things I strive for is to integrate the whole human body, which has been quite a challenge in our health system applying the knowledge that's generated from NIH. And we strove to develop a patient centered medical home model expanding on what the pediatric community has developed and we did an 80,000 person pilot project with highly successful results, recognized nationally, and it is now into the community health center model. In fact, they just received distinction as an example of a national model.

This is the Blackstone Valley Community Health

Center. They have electronic health records. They serve uninsured and underinsured population. They only have about ten percent insured population with other payers and their results because they have the outcomes, they are doing quality control-- their results rival the best system anywhere for private care patients. So this can be done following some of the prototypes envisioned, I guess, in legislation and what we're attempting to do with patient outcome centered research, translational science.

Now the community health center could assist the NIH and their grantees in clinical trials and be a real important member of this community.

MR. LEWIS: Hi. I'm Jordan Lewis. I'm a research scientist with the Center for Alaska Native Health Research at the University of Alaska, Fairbanks.

What I've been observing is we're seeing an increase of NIH funding in Alaska, specifically on biomedical research looking at genetics of obesity with Alaska Natives, as well as behavioral health, and as a result of this we're seeing more appropriate interventions being developed, programs and services. And it's my hope that we can get more Native students

involved in this research.

MS. LEONG: Hello, Dr. Tabak.

I'm Amye Leong from Santa Barbara, California. I serve--I do consulting in patient advocacy and communication and translation of research and I for the last ten years have been serving as the international spokesperson for the United Nations Bone and Joint Decade and so at the National Institute of Arthritis, Musculoskeletal and Skin Diseases I work very closely with Steve Katz and his wonderful team.

The area of biomedical research has for me personally been very, very beneficial. I mean I used to be wheelchair bound and now I'm not because of the advances in research. I have been asked quite a few times this, particularly once at the 25th anniversary of NIAMS for which Dr. Collins was a keynote speaker at and I also spoke at, to talk about what those benefits are and how they actually translate to the human function or getting people back to work, getting someone like me off of Medicare disability back into a functional taxpaying citizen role. So very, very important. Also, the other conferences are two national summits. One on musculoskeletal disparities because of the access to care

issues for people of underserved and people of color and racial disparities particularly in musculoskeletal disorders. And then also the value of musculoskeletal care.

What we see is the translation of biomedical research into the important role of what care does but what is the value of that care from the economic and human perspective, and particularly with lessening budgets these days.

What I also am observing is that NIH is playing an important role in the development of the Health and Human Services strategy/strategic plan on multiple chronic conditions. And because I'm one of those people I know now the next stage is to begin reviewing that to see how that is implemented. So, as some of my colleagues have said, the public engagement of that--I think we're here--we definitely are here for you to do that and would like to be a part of that.

Thank you.

MS. CHURCH: Good afternoon. (Indian language not herein transcribed.) I am Navajo and I am from Albuquerque, New Mexico. A change that has occurred is that I am no longer working for the New Mexico--

University of New Mexico but I have taken a position with the New Mexico Public Education Department in the School and Family Support Division. A couple of things that I wanted to share with you--today I'm--the hat I'm wearing today is a community member.

A couple of things that I wanted to share with you and just express my appreciation. Number one is congratulations to NIH for the National Library of Medicine's 175th anniversary and for featuring the Native American, which is my background, my culture, my traditions and my world view, in expressing health and wellness and healing. And a thought to that was looking at--you know, there's two realms that I see. You have my Native world view, our Native world view, and then you have the scientific process for discovery and really taking a look and challenging NIH to look at how you would respectfully integrate those two realms.

I think the benefits that would come out of that is, number one, a diversified workforce; number two is the innovation to discovery, especially when you're looking at encouraging young American Indian scientists; and then the third, of course, is just strengthening the stakeholders' engagement into that process. I think

that’s important.

Another piece that I wanted to share in my appreciation to NIH as a student because I just recently received my Masters of Public Administration and Masters of Science and Health Education, a double masters from UNM, and just the wealth of resources that are available from PubMed and how that really assisted me in my graduate work when I looked at health education work and studies for the Native American population. And so on behalf of myself as a student, thank you very much.

DR. TABAK: Thank you.

MS. APPELL: Thank you, Dr. Tabak. It’s lovely and wonderful to be here certainly in this room with these very talented consumers. I am Donna Appell and I am the founder of the Hermansky-Pudlak Syndrome Network. Hermansky-Pudlak Syndrome is probably the number one genetic disorder of Puerto Rican people and I do a lot of work in trying to help in Puerto Rico and it’s certainly an area that needs more attention.

When we talk about biomedical research I just really want to take a minute. You know, I mentioned that we are a genetic disorder and I have to celebrate the NIH. I love it dearly and I have to, you know, say that

the genetic research is applauded this month because of Family Health History Month. And I am a registered nurse myself so I practice, you know, speaking with families very often and we are now really making great strides in having people understand and connect the dots between their genetics and their own health. The story of their parents and their grandparents and their health and how they really understand that it relates to a personal health and how they can make changes. So I have seen over the years how genetics has impacted people's personal lives and I think they understand so much more and I applaud the NIH for all its efforts on behalf of National Family Health Month.

MS. LAPHAM: Hi. I'm Gardiner Lapham and one of the--one of my interests is epilepsy. One of the things that I've been very encouraged to see lately in the news and to see more research on is head injuries in sports as well as there's an increased look at the number of vets that are coming--returning to the U.S. who have head injuries, especially post traumatic epilepsy. So I'm encouraged to see there is more public discussion about that but also more research in those areas not only at NIH but across other agencies within the federal

government.

Thank you for that.

DR. WOOLEY: I'm Susan Wooley. I started a new job this summer as the executive director of the Director's of Health Promotion and Education, whose members work in state health departments on health promotion, health education and health equity, and really take a systems and environmental change approach to health.

I remember when I was in high school hearing an NIH researcher give the results of a study of tobacco and the effects of it on human health, which was not--it was a long time ago. And what I want to comment on is that over the years we've held the basic science but now NIH moving also into the behavioral sciences research is important because just because we have the biological or biomedical science doesn't mean it translates into what people do in their health.

And then the need now for being cross disciplinary and, as I said, systems and environmental change, recent research that I have heard was that of all the tobacco consumed in this country 30 percent of that is by people with mental illness. So what are the

connections between mental illness and substance abuse and how people make decisions and are--you know, and so often we are siloed so that we are not looking at those cross connections and how those might impact the nation's health.

MR. NYCZ: Hi. I'm Greg Nycz. I run a large community health center in North Central Wisconsin in partnership with Marshfield Clinic and we have a very large Dental initiative going on and our last fiscal year we served over 41,000 individuals through our dental clinic, our expanding network, and that activity caught the attention of one of the NIH funded bench researchers by the name of Yiping Han and I have the tremendous good fortune to be able to hear her present some of her work. And she presented to our provider community and our research community but also some of the people like me who aren't scientists but run programs. And I have to say as a non-researcher she had me at the edge of my seat because she was basically telling a very interesting detective story.

The point that I want to make is she made a difference in decisions we will make going forward in trying to give better care to pregnant women. And you're

going to hear from our team here about how we could maybe scale that up to make a much bigger difference nationally.

MS. AARONSON: Hi. I'm Stephanie Aaronson, Fairfax, Virginia.

Right now I am doing some communications consulting and helping get a website off the ground called Citizen Jane which is getting young women involved in politics and making sure they vote.

As a mom and a very involved family member, I'm really excited that the obesity working group is finally pulled together and working across agencies. One of the key things that having worked in obesity in public media to look at what's happening in the community at the local level, what are the factors of influence and actually getting NIH to come forth with some research to know why this is happening and how we can change it because I have seen a lot of money being thrown into communities and the evaluations have not been great nor are they telling any kind of solution stories. So with your capabilities I'm sure you'll turn it around with all the research you do. So that will be exciting to see.

MR. PAVAO: And finally Carlos Pavao. I'm

actually from Atlanta, Georgia, and my expertise is HIV, substance abuse and mental health, looking at the intersections of that. And I actually work with states, Tribes and jurisdictions around those issues.

One of the things that I've noticed is that there are controversial public health topics for certain states or certain regions are a little more conservative in looking at it and what I've noticed where I'm from is that anything to do with reproductive health, HIV, anything to do with sexual health issues tends to get the attention of the local legislature. Especially if they are public universities that actually has a drastic impact on funding, local funding.

One of the things that I've noticed--and this has been playing out already in the media in Georgia--is that researchers--and also their partners--are not necessarily well prepared to deal with that kind of controversy. So what that does is it creates sort of a, you know, why are we spending these dollars on X, Y and Z and, you know, should we be doing this.

And another topic could be also stem cells and, you know, there's a lot of those controversies.

So what I would love to see--and I know there's

a lot of great work here at NIH--is how to sort of increase the capacity of local researchers and their partners to think proactively about sort of, you know, crisis management when it comes to issues in the public.

DIRECTOR'S UPDATE

DR. TABAK: Well, thank you all.

I have to say each of you said something that resonates with me. It's a little bit of a cognitive test so I'm going to start with the last comment first and we'll see how far I get but certainly on a federal level, as I'm sure you're aware, on occasion organizations will call into question why there is federal funding for certain types of research activity. And actually John Burklow and his outstanding team together with folks within the institutes and centers are very proactive in being able to explain why the science is, in fact, so important.

I'll give you one example that I personally got involved in. In fact, there's evidence of my involvement because it was on NPR radio and my son called me very early in the morning and said, "Was that you on NPR?"

So somebody took issue with a study involving nail clippings. They thought this was the silliest

funniest thing. Why would NIH spend hard earned taxpayer dollars on nail clippings? Of course, it was a biomarker study to measure tobacco exposure. And so when you put it into that context, into the scientific context, it didn't seem so silly anymore.

And so we all need to be quite vigilant and it starts with communications and John and his colleagues are able to help us as scientists craft a message in a way that is readily understandable but is, you know, true to the science and that's a real art. So, yes, I can appreciate that this is occurring on the local level but it also occurs on a federal level.

All of you who mentioned dentistry, thank you so much. It's so rare that I--you know, I don't get to do that anymore but thank you all so very much.

I think your comments about mental health and addiction or substance abuse is one of the reasons why NIH is moving towards a recommendation that the Scientific Management and Review Board made to create one single entity at NIH to study substance use, abuse and addiction research. And on the table and, in fact, as we speak in real time is the analysis of the portfolios of all institutes and centers from across the NIH and things

like tobacco cessation, that is the addictive qualities of nicotine are very much going to be part of this new entity, whatever the final name really is. So that--I mean you said it better than I've been trying to say for months and months now so I do thank you for that.

I think, you know, the whole issue of getting people of all backgrounds into the biomedical research workforce--I'm going to speak to that more formally in a few moments but this is so, so important and this is something that NIH has been trying to do for over 30 years and we are falling way short of where we need to be. And whilst I know that we need all of your help, we need all of your public input on so many, many different things, that question is probably one of the foremost ones that we need your help with. And I'll show you some data which I think will prove the point.

So I think we--oh, and then I can't help but--see I'm having all this fun stuff here. So you mentioned head injuries and, of course, there's a tremendous emphasis on our men and women who are coming home from their service duties but, you know, young kids in sports. I was a basketball official for many, many years and you might think that basketball and head injuries are not

really synonymous--okay, so now you all know why it is. It gets transmitted up through the jaw and, you know, so it's real. And for years , you know, we've tried to convince young kids to wear mouth guards playing basketball because it dissipates the force. But, of course, their coaches yell that you can't communicate. Until we taught them some sign language and so at least one point guard in the early 2000's worth a mouth guard and was able to communicate with his team just fine into the state second round championships. My younger kid.

(Laughter.)

So anyway, okay.

And to everybody else, sorry, I couldn't make connection but do resonate very strongly with your comments.

Okay. So let me, if I may, give you sort of a quick update on several issues. I have heard--is that right? Am I--yes. I'm just following my cues. I'm going to go up there.

(Slide.)

I understand that John Burklow covered a couple of things this morning related to NCATS so when we get to those slides they are going to be really familiar and I'm

going to fast forward, which will give us a little more time for some of the other issues that perhaps he didn't. But if you see something that you've already heard today just raise your hand and we'll fast forward.

So I just wanted to do a quick environmental scan. I will fast forward through NCATS. I do want to spend a fair amount of time on the discussion about diversity and the biomedical research workforce because we really do need all of your help, all of your input. And then talk a little bit about economic impact unless John covered that as well.

So the scan. This graph depicts the appropriation of NIH from 1998 through the current fiscal year. Now, of course, we don't have a budget yet so really we should just sort of have a big question mark here. The dark bar represents the actual dollar appropriation and so beginning around 2000 or so you see the start of the so-called NIH doubling and that was such a spectacular time and so many opportunities were realized. And then we unfortunately sort of leveled off through the 2000s and then in 2009 and 2010 these light bars designate the miracle known as the Recovery Act. And it really was a miracle, an infusion of $10.4 billion

into NIH, which allowed us to do so very, very many things. And what I think the data and analysis will ultimately show is that infusion, that investment will reek benefits for many, many, many years to come.

Just early this morning we were hearing about some high throughput cold genome sequencing projects that are ongoing. Some in the cancer field, some in the cardiovascular field, several in the mental health field. Most of that was fueled by the Recovery Act dollars and we're just now beginning to have access to this very, very rich dataset. Again I think we'll derive benefits from this for many, many years.

And then we sort of got back down to reality again but what is more of concern is that the yellow bar are our appropriations indexed against 1998 dollars. So this is our real buying power and so whilst our absolute dollars haves increased and have sort of leveled off and then had this amazing jump and now have leveled off again, what you see in terms of buying power is we're sort of back to where we were in 2002 or so.

And, of course, we still don't know what our fate is for this fiscal year and, indeed, we are already knee deep in contemplating what 2013 has to offer and

beyond. It's not a pretty sight and I'm not revealing anything that's not in the lay press each and every day. We have super committees and all sorts of triggers and, frankly, given the actual buying power and given the ambiguity and uncertainties going forward is there any reason to question why young people when they're contemplating career choices think, gee, should I really go into biomedical research or should I take any one of a number of other opportunities?

Now, I guess the only good thing about our 401Ks becoming 201Ks is that very few of our young people are going to Wall Street anymore but apart from that advantage, you know, there are many other career choices that young people can make and this is partly, you know, why I think they are making some of the choices they are. They see their professors struggling. They sort of wonder, gee, is this really what I am looking forward to doing for the next 30-40 years of my life?

(Slide.)

So I'm going to fast forward through this only to say that if you have not had an opportunity to read this policy piece in Science Translational Medicine you might want to because it's beautifully written and it is

written in a way that I think lays out the logic of what the NIH is trying to do with the creation of this National Center for Advancing Translational Sciences. Apart from the cool acronym, I do think that the logic, you know, is irrefutable. And again the center's activities are going to complement and not compete with what's going on in the private sector.

Early on there was a bit of a misperception that somehow NIH was going to move all translational activities across the agency into this new center and, indeed, that's not the case. The National Cancer Institute will continue to do its translational efforts and so forth. All the institutes and centers will continue to have a very robust presence in this space but we hope that this proposed new center is really going to be catalytic and help all of the translational efforts both within the agency as well as in the private sector.

(Slide.)

So a good part of that is going to be NCATS's emphasis on catalyzing partnerships because what we have learned as we analyzed, you know, with some rigor the whole translational sciences space, what you very quickly understand is that NIH alone can't pull this off. We are

obligated if we have any hope of succeeding to engage all of these groups as partners. So the advocacy groups are equally important to pharma, biotech is equally important to the not-for-profits, international efforts are equally important to academicians and let's not forget our sister agency, the Food and Drug Administration. So all of these partnerships are going to be crucially important.

And whilst individual institutes and centers do this, and some of you alluded to this in your introductory comments earlier, we need to do more of it and the hope is that NCATS will serve as a fulcrum for new and additional opportunities of this type.

(Slide.)

So if you go to the NIH homepage of which this is a screen shot, there is a button towards the bottom of the homepage, "advancing translational sciences," and if you click on that it will give you a great deal of information about translational activities in general across the agency.

(Slide.)

So this is really what I wanted to spend the majority of my time speaking to you about. Some recent studies on the diversity of the biomedical research

workforce.

(Slide.)

So on your left is a pie graph which depicts the census of our nation in 2010. And it may be a little difficult to read the legend but let’s focus on the 16.3 percent of our population that is Hispanic or Latino and the 12.6 percent of our population that is Black or African American, and then the 0.9 percent American Indian or Alaskan Native, and then the 0.2 percent of Native Hawaiian or other Pacific Islanders. Those are the individual groups that are underrepresented in science and so the question becomes how underrepresented.

And by comparing the race and ethnicity of NIH principal investigators on research project grants from across the agency--so this is aggregated data--it doesn’t take higher math to observe very quickly that Black or African Americans are woefully underrepresented, 1.1 percent versus 12.6 percent, those of Hispanic or Latino background are woefully underrepresented, 3.5 percent versus 16.3 percent, and frankly the numbers of American Indians and Alaska Natives and Native Hawaiians and other Pacific Islanders are so tiny amongst our principal investigators that there is no--there is nobody there.

It’s just too small a number.

Now, there are many, many, many reasons why we have this disconnect from the general population to an NIH principal investigator. Some would argue that it begins prior to kindergarten. Others would say the issue is K-12. Others will--you know, so--and every one of you if I went around the room--every one of you could list five or six or ten reasons why we have this extraordinary disconnect. But just because we can each describe why it’s occurring doesn’t mean that we shouldn’t begin to address how to redress this issue because what typically happens is, oh, it’s K-12 and then there’s a bunch of hand waving and then you move on to the next issue. And we can’t do that anymore and I’ll elaborate as to why not.

(Slide.)

Just to give you a sense of the magnitude of the problem, this is a part of the pipeline that is closer to the NIH mission, if you will. Now, just to preface K-12, my wife has been a second grade teacher for over 25 years. Trust me I understand how important elementary education is. All right. But I think you would all agree that individuals in the Baccalaureate,

Ph.D., post-doctoral positions are closer to what the NIH mission is. So let's just focus on that for a moment.

Underrepresented minorities make up a third of our college age population and that's pretty good because 25 years ago that was not the case. But they only make up 17 percent of the young people who earn a Baccalaureate in science or engineering. So there's this tremendous drop off and further drop off occurs at the level of earning a Ph.D. in science or engineering. They make up only seven percent. So only seven percent of this group actually goes on. And it's a constant distillation.

(Slide.)

Now, let me show you numbers to underscore the challenge that we're facing. And let's just focus on the Ph.D. total for a moment. These are Ph.D.s awarded from 2000 to 2008 in the biological sciences, chemistry and physics to citizens and permanent residents by U.S. institutions. So again this is aggregated data.

Each year our nation is only producing about 400 new Ph.D.s amongst underrepresented minorities in these categories. So think about that for a moment. Only 500 each year to fill all the positions that one

could imagine an individual filling with a degree in biology, chemistry or physics.

We could give--if I could wave a magic wand and give everyone of these young people an NIH grant today we would still be woefully underrepresented relative to those two pie charts that I shared with you a couple of slides ago. So even if we could fix it and every one of these young becomes an NIH grantee, we're still woefully underrepresented.

(Slide.)

So we are thinking that one place that NIH might be able to make a difference, and this is a question mark because we really don't know, is the transition from the Baccalaureate to the Ph.D. , non-underrepresented minorities make that transition, about 10 percent of those who receive a Bachelor's degree ultimately receive a Ph.D. but underrepresented minorities only receive that at a five percent rate. That means that we need to at least double, at least double the number of underrepresented minorities making this transition to maintain the current proportion of our population.

Why emphasize that? Because, as many of you

know, by 2042 minorities in this nation become the majority. And we are beginning to enter a perfect storm. If you go into any laboratory in this country and say, “Do you have a diverse laboratory workforce?” I guarantee you people will say, “Yes, I do. I have someone from Korea. I have somebody from India and I have somebody from China.” And that’s about as diverse as you can get. And it’s reflex. I mean they are not trying to be glib. So in that context, yes, biomedical research is very diverse but that’s, of course, not the diversity we’re speaking about.

So if you have a nation where the minorities are going to become the majority certainly within many of your lifetimes, you have a circumstance now where the economies around the world are booming except here so that it is becoming increasingly difficult to recruit the scientific talent of other nations to come to the U.S. and, indeed, once they are here more and more difficult to retain them because more and more of these young people are repatriating. You can see that we’re going to have a circumstance where unless we are very, very proactive who is going to make up our biomedical research workforce in the future.

So I asked scientists around the country imagine a circumstance where we do not have a seemingly endless supply of foreign research talent coming through our nation and underrepresented minorities are not going into the sciences, we're doing a horrible job of recruiting them and encouraging them and enabling them--and, oh by the way, they're going to become the majority of the population within the next 30 years or so--who is going to replace, you know, the fast aging, you know, boomer generation? This is a perfect storm. It gets even more challenging.

(Slide.)

So in mid August a paper was published in *Science* magazine entitled "Race, Ethnicity and NIH Research Awards." Now, I want to emphasize to you that this was an NIH commissioned study. Wally Schaffer continues to work at NIH and Raynard Kington, who is the senior author, the last author, was my predecessor's deputy director. So this is very much an NIH study. This was not, you know, an uncovering something. This was an NIH sponsored study.

But what this study did was it uncovered racial disparities in our grant awards. So putting this into

context, I've already told you we don't do a great job of recruiting under representing minorities into the pipeline. What I'm now going to tell you is the very, very few that are in the pipeline, we're not doing such a great job of rewarding them through grant awards.

(Slide.)

So here is the study at a glance. For statistical reasons only Ph.D. investigators were studied. Now think about that for a moment. For statistical reasons. That means there were an insufficient number of M.D. researchers who are underrepresented minorities to have sufficient power to include in this analysis. So we're only looking at Ph.D.s. The trends are the same for the M.D. researchers but again for the purpose of the statistical analysis only Ph.D.s were looked at.

So they looked at 40,000 or so Ph.D. investigators from the year 2000 to 2006. Those individuals contributed 83,188 R01 applications. That's our gold standard application. It's sort of a yardstick by which most places measure the quality of their faculty and research efforts.

Of those 40,069 unique Ph.D. investigators,

1,149 were from Black Ph.D.s. That is from the 83,000 applications, 1,149 were submitted by Black Ph.D.s. And I'll stop for a moment. Of 83,188 applications, only 1,149 were submitted by Black applicants. If Black applicants would receive awards at the same level of success as White applicants you'd expect them to have received 337 awards. Only 185 awards actually went to Black applicants. Again that's all things equal. Okay.

So these data are trying to take into account from statistical means all manner of issues that you would expect might influence whether or not somebody would be able to receive an NIH grant award.

(Slide.)

Now, there's some additional not so great news.

Award probability is correlated with NIH funding rank of an applicant's institution. What that means is, is that if you were at a top 30 organization in terms of NIH total funding you are more likely to get an award than if you are an organization that is 31 through 100. And in data that's not displayed here if you're at an organization 101 through 200 you would be here and if you're at an organization that's 200 or less, meaning this is a very--a non-research intensive environment--

you'd be sort of down here. And there's sort of this straight line correlation.

Now, some people think, well, sure, that's why they are top 30 organizations. When other people look at those data their heads explode. I mean why should somebody at a top 30 organization enjoy this much of a difference in award probability than somebody from 31 through 100?

But in each rank group Black Africans have the lowest award probability. That means that even if you are at a top 30 organization, if you're Black or African American, you are still not receiving award at the same rate as your majority colleagues. And that persists at all of the rank levels.

Now, curiously if you're at a top 30 and you're Black you're doing better than a majority individual at a 31 through 100.

So this is very complex stuff and we could, you know, come up with all kinds of ideas as to why this is or why it isn't but the fact of the matter is that the disparity, the differential success rate, persists even at the very finest institutions in the country. So it's not a simplistic, well, the majority of Black African

American applicants are at less research intensive environments, they don’t have the infrastructure, you know. No, even if you’re at a top 30 there is still this discrepancy.

The only thing that seems to matter--the only thing that reduces the disparity for Black Africans is their citation record. That is how well their work is received by the scientific community as measured by other people’s citing their work or prior review committee experience. Now that is a conundrum. Some of you are very familiar with the NIH system. Others perhaps less so.

So basically you don’t get to be invited to review grants until you, yourself have a grant. The conundrum is you don’t really learn how to write a grant until you review a grant. Hmm, now what do we do? Right? So, you know, have you ever seen a dog chasing its tail? I mean, you know, it’s--so I’ll share with you one approach that we’re using to begin to help redress some of this and it has to make more accessible the opportunity to serve on review panels.

It turns out that if you participate in some sort of form of NIH training or career development, that

has a positive effect. But for reasons that we don't understand, it helps Whites more than it does Blacks or Asians.

So we have the data now. And so the question is what are we going to do with this? Now, I will tell you when we shared these data with members of the Black academic community, many of them looked at us and said, "I could have told you that. That has been going on for years." And even though the data say that there is no difference between White or Hispanic investigators, many Hispanic or Latino investigators will say, "Now wait a minute. You're lumping all Hispanics and Latinos together. If you look at Mexican Americans you would see the same type of disparity." And obviously we don't have enough in the way of numbers to even make a statement about American Indians, Alaska Natives. Those groups are just so small there are no numbers of this type but no doubt the same disparities are present. Otherwise we'd have a much greater percentage as principal investigators.

(Slide.)

So in that same issue of *Science* Dr. Collins and I offered this policy forum and in this we laid out

our plan of action because the reaction of most people when this all came out was either, well, I could have told you that a long time ago or, oh, my goodness, what are you going to do about this or something in between. So these are the things that we're doing about it and I wanted to share this with your group because no doubt you will be able to think of additional things that we should be doing about it. That's the whole purpose of discussing with members of panels like this.

(Slide.)

So the first thing we're going to do is we're going to increase the number of early career reviewers. The Center for Scientific Review, which is responsible for roughly 70 percent of the reviews that are done at NIH, across the NIH, now has this Early Careers Review Program and what they have done is they have reached out to a much broader diversity of institutions. Institutions that are much less research intensive, institutions that typically we don't have many reviewers from and, interestingly enough, many of those institutions are very enriched in a much more diverse workforce. So think for example HPCU. Think for example Hispanic serving institutions and so forth.

Now, in addition to this outreach, there is also the opportunity for people to self nominate. And so if any of you know of a bright scientist who has not yet received an NIH grant but you think is at a point in his or her career where they would be able to make a contribution as a reviewer, please if you could get that information to them that there's a way of self nominating or send the information to me and I'll connect them that would be an enormous help for us. Particularly those of you who are at institutions that we are typically not reaching out to.

Now we are going to look at the grants review process for bias because even though we don't want to believe that in 2011 there is still bias, we have no choice but to consider that as one possibility. Again, for those of you who are not as familiar with our grants process, when a reviewer gets a grant application there is no indication on the application that the reviewer sees of the applicant's race or ethnicity. But so much of our review criteria are steeped in the individual's prior experience to ascertain whether they are or are not capable of conducting the research proposed that you include bibliographic information. And so in many

instances based either on a surname or where an individual has trained it is possible to infer race or ethnicity of an individual.

And I don’t know if any of you have run across Project Implicit. It is a consortium project looking at unintended, unconscious bias. If you just Google Project Implicit on the web you’ll find it. They take--they have a series of anonymous tests that you can take. I have done this. I will tell you the results are unbelievably sobering. At least they were for me. So it might be something you want to do some rainy afternoon.

We need to improve support for all of our applicants. You know, in the good old days--I’m beginning to sound like all those old people that I swore I would never become but here I am, I’m there. In the old days when you were a member of a department, your departmental chair never let your grant application go out until he or she reviewed it, made comments, and then you followed the recommendations and only then did you send it out. I think that the pressure on investigators today is so much greater than it was in the good old days that increasingly less and less of that mentorship is occurring. So I think NIH needs to partner with

applicant organizations to figure out ways of bolstering our mentorship work for grant applicants.

And then this last piece, that's why we're here--I mean one of the reasons why we're here--to try and get the best advice from you all as to the types of things that we should be doing. Now, again what I've described is a problem that is multifactorial and has many, many levers that one could potentially adjust to help redress things. This most recent discussion--that's at the very, very, very far end of a pipeline. People who make it through everything, apply for a grant and, sadly, things don't work out the way they should. So we need to redress that.

But way back here, and again I'm not being dismissive of K-12 but even if we just start at the Baccalaureate to Ph.D. transition we have far, far, far too few kids from underrepresented groups who are even taking that pathway.

Now, I mentioned earlier I was a basketball official for many years and I can't tell you who many times I would see a kid in what they now call middle school, we used to call it junior high school, who decides not to take algebra. Well, once you decide not

to take algebra the game is over. And it's not that we shouldn't have historians and lawyers and artists. I mean that's all wonderful. But once you decide not to take algebra you are not going to get a Ph.D. in physics or engineering unless something remarkably happens along the way. So we have got to figure out what else we can do to redress this.

(Slide.)

Okay, so I'd like to just quickly finish up and to share with you some numbers. The last time this group met I thought--as I recall there wasn't a discussion about economic impact.

(Slide.)

This is just some of the more recent things that people can point to. So there is this increased life expectancy, reduction of deaths because--from these various diseases and conditions, increased survival rates for a number of forms of cancer. This translates into over $3 trillion a year according to the economists. I'm not sure how you put a price on a life but that's where--in terms of productivity and so forth.

Cardiovascular disease death rates have fallen greater than 60 percent.

HIV therapies--now this is the most remarkable thing. The National Institute on Aging is now talking about what they should do research-wise for individuals with HIV/AIDS. Think about that for a moment. I mean if you think back to 1979 when this all first--we became aware--would anybody have thought that the National Institute on Aging would be--so that's a victory of sorts. It doesn't mean we're there yet but it is quite remarkable.

And then, of course, cancer rates keep falling. And every time it falls one percent, it saves the system $500 billion. So this is nontrivial.

(Slide.)

And the additional good news is people are living longer but their quality of life also continues to improve. You know, living longer with a poor quality of life is no picnic. But if you are living longer with increasingly less disability, and that is the case, that is--everybody would sign up for that.

(Slide.)

Now, in terms of the sort of local NIH supported research on the economy. In 2010 we supported just under 500,000 jobs. That's a pretty good economic

engine. $68 billion in new economic activity is twice what gets put in. I know if I could find something that would give me twice what I put in I would definitely sign up for that. Actually I'd take 1.1 percent if I put in money. And there's this foundation that NIH serves for in terms of the whole medical innovation sector, you know, it's over a million people when you count up everybody. $84 billion in wages and salaries, export of $90 billion. So that's a pretty good investment of $30 billion at least by my calculation.

(Slide.)

So I just would like to just finish up with this quote from Jim Shannon who was the eighth director of the NIH. It's a quote about basic research because, you know, everybody is so very convinced that NIH needs to do more in the way of tangibles and we need to do a better job of translation, and all of that is true but we really do need to continue our investment in basic research as well. "The hope of major advances lies in sustaining broad and free-ranging inquiry of all aspects of the phenomenon of life, limited only by the criteria of excellence, the scientific importance, and the seriousness and competence of the investigator."

We can track back virtually every blockbuster pharmaceutical, great discovery which has increased life expectancy, great discovery that has reduced disease, burden of disease, to some--at the moment it was discovered--some seemingly arcane scientific finding that at the time most people would look at and say, “Well, that’s really nice.” We are not really understanding why it was so profoundly important and we need not lose sight of that.

So whilst we have to do a better job translating and we have to do a better job capitalizing and exploiting all of the great discoveries that emerge, we can’t lose sight of this piece as well.

So with that I will stop and if people have any comments or questions or suggestions I am all ears. I’m going to go back to the table.

DR. WASHINGTON: Just really quickly before we start since we have gotten a little agenda. We’ll spend about ten minutes on questions. If you can please keep your questions concise. And if you have multiple, ,can you just do one at a time just to make sure we at least give everybody who has a question an opportunity. And then we’re going to break at 2:45 to do the photos and

then if there's additional discussion we can do it at that time.

So I'll let Stephanie and Carlos--you can manage their questions.

MR. PAVAO: A couple of suggestions. One is as you're looking to increase diversity don't forget--and this comes from some of the dental pipeline studies as well as some studies in medicine--that with increasing cost of education we should not forget what they call LI populations, low income. You can get minority populations who are not low income populations. And so keep that going and recognize that the work that you've got going in the K-12 is a major impetus towards that.

And then, secondly, the pilot--you know, most people, I think, feel that in order to get an R01 you can't just come out of the box with it. You have to have pilot studies done on that.

And have you looked at the extent to which some of these institutions may be doing a better job supporting the pilot work and that could be part of the problem here?

DR. TABAK: Yes. So with regard to your first comment you are absolutely correct. You know, I'm scared

for the current generation of young people. I'm old enough to have been privileged to grow up at a time in New York City when a college education was free. I went to City College and if not for City College and the tuition being zero I would not have gone to college. You know, full stop. And if I had not gone college I probably wouldn't be sitting here today. A pretty good bet. And, unfortunately, those options don't exist for the most part anymore.

Now, a place where a lot of great work is being done is in the community colleges. I was just down at Dade College in Miami a few weeks ago and they are doing some spectacular things with young people. Many Hispanic Latinos but people--you know, all backgrounds.

With regard to the second point, you know, we are seeing the disparity in the top 30 institutions so it's not just resources but it may be that there are a subset that do a better job than others. It's something that we need to think about.

MR. LEWIS: Thank you for your presentation. One suggestion--you were talking earlier about the really low rate for American Indians and Alaska Natives in the pipeline. I wasn't sure if you guys do any work with the

Association of American Indian Physicians. I know they have a summer internship program for college students that are interested in the biomedical or health fields.

DR. TABAK: Yes, so the short answer is we do. And everybody has an anecdote of the one young person that they have either mentored or interacted with who has done well and gone on. But when you roll up all the data we're still falling way short. I kid people. I say, you know, "The plural of anecdote isn't data." And sadly in this case that's true.

We have--you know, here at NIH we've got great summer opportunities. We virtually never get a young person from Indian country. Now part of that is because of the costs because there are some inherent costs but we get very few--we get even very few inquiries. We can't even have a conversation about what might or might not be possible.

So somehow we've got to do a better job of getting the word out that there are these opportunities. Some people have said we have got to do more to support the local activity where it's more likely that young people from these groups would, you know, participate.

DR. OLSON: So thank you so much for that great

presentation. I will definitely take you up on your offer of going back and looking at my network to identify minority candidates to be reviewers.

I also just want to make a suggestion going back to the discussion on the translational park. You have that diagram there with the wheel of the different groups involved. I think there's one group that I would argue should be there that isn't. If we're going to take translation to the bedside because ultimately unless the providers are involved in changing behavior it doesn't-- it's not going to matter. So I think they need to be part of that wheel, the health care providers.

DR. TABAK: A fair point and thank you.

MS. CHURCH: Thank you, Dr. Tabak.

(Crying.) The presentation just really strikes me when you say who is going to make up our biomedical community. It's all of our communities. But coming from my world time and time and time again the American Indian population is too small. It's not statistically significant. I hear that over and over and over again. As a recipient of this message and as the recipient of that statement that strikes me.

So number one is taking a look at the

statistical calculations of how we make that significant. Number one.

Number two, you say NIH needs to do a better job and maybe--you know, I'm going to go out with a bang because this is my last official meeting. NIH has to step out of the gates of NIH. You have to go down the road to Indian Health Service. You have to talk to Dr. Yvette Roubideaux to say how can we work in partnership. There is a lot of Native communities that have a strong tie to Indian Health Service so there is your neighboring partner.

Another neighboring partner is the American Indian Science and Engineering Society. Another one is the National Indian Education Association. Another one is the U.S. Department of Education--Indian Education. Another one is the National Congress of American Indians. And another one is the American Indian Tribal Colleges and Universities.

I am not sure if anyone remembers but I'm going to remind you that one of the former COPR members was Dr. Cynthia Lindquist Mala. She was a Tribal president from North Dakota. She is another resource that understands COBRA, that understands and can allocate how we can help

increase the numbers of the Native scientists and get involved in biomedical research. I know it's important and that's why my passion is here. I have to speak up. I have to just say why it's so important and that we have to spread the word to our young people but as well as also understand that we look at the scientific world and how does that correlate and support the Native world view.

I gave an example yesterday in our meeting when you look at even the consent forms there are some correlations with the consent forms that support my world view. When you look at the teachings of honesty, kindness, sharing and respect. When you look at the teachings of honesty there is your transparency. When you look at the teaching of kindness look at your methods in your protocol. When you look at the teaching of respect there's your privacy and confidentiality. And the last is your sharing is your dissemination.

I am throwing that on the table to just have NIH really take a look at the scientific aspects and really start integrating how that fits into the Native world view. Don't just showcase Native American health, wellness and healing in the library. I am very--you

know, I'm so appreciative of that but let's go further and beyond and look at the 27 institutes and centers that can really help promote this. We have to make a change. Things are happening in our U.S. population that is changing the dynamics of our country. We have got to be ready and we've got to be ready to meet those challenges with our young people.

I'm a mother of five. You know, I value education. My husband values education. We keep, you know, pushing our kids to just excel in school, excel in sports, excel in the Junior ROTC program. We're doing many things in that way and I just feel like that message has to be so much integrated with the NIH language that's an institutional language of how you integrate Native American health, wellness and healing in the scientific parameters of NIH and beyond, beyond the gates.

I'm sorry but I just had to express that because that message speaks so much to me and I will just carry that message on to these other organizations that I mentioned. I don't think we do enough of communication. I don't think we do enough of having to set conversations. You know, having an academic journal article here is important and I'm thankful for that, that

it is being disseminated but I think we need to have that conversation and I challenge NIH to start having these conversations with these organizations.

If it is then continue that conversation because we have to make a difference on behalf of not only the Native American population but all other underrepresented minorities because the world is changing and we have to change with that world.

Thank you.

DR. WOOLEY: In a way this follows up on what Lora was saying, although maybe not with the same passion. I think that part of the reason in my experience, and I've worked in a Historically Black College--I--where I'm working now we're doing a lot of work on health equity. There are many of the underserved populations who feel that a lot of biomedical research in the past has exploited them, that they as a community don't benefit from that and they are taken advantage of, and that contributes to the workforce issues. So we're not going to address all of those until we can build trust in communities that have been negatively affected in some ways.

I'm wondering if there was any examination of

the content of the application of the research studies and whether in terms of discrimination if they address an issue that brings a different cultural perspective, whether it's Native American or African American perspective, and whether this is viewed negatively by the reviewers who might tend to come from a different cultural background?

DR. TABAK: So, in fact, an analysis has been done about the field of study because that was one of the first things that people thought might help explain the findings. So using study sections as a surrogate, for example, looking at the study sections that review health disparities research, there is a disproportionate number of individuals who are Black or African American. There was no difference in the success rates.

What was telling was the reverse. There are virtually no Black or African American applicants submitting grants in basic science. Virtually none. It's stunning. So there's a disproportional representation in health disparities research, in behavioral and social sciences research in general, in clinical research, and again none of that is bad. I mean that's all wonderful that people are applying for those

fields but it is stunning that there were virtually no Black or African American scientists submitting NIH grants in basic science.

So, yes. Do I want to see underrepresented minorities redress health disparities? Of course. But I also would like to see some of these young people getting degrees in biophysics.

DR. LEONG: Dr. Tabak, you can see that this obviously is a very passionate subject for us who represent our various diverse communities from wherever we come from. We spent yesterday--a great deal of yesterday and the previous meeting really drilling into the depths of what Tony Beck (ph) talked about in terms of the science and education program getting down to really elementary school levels and moving it forward.

There are many programs that are beginning to address this and, like as you said and implied, this doesn’t happen overnight. The problem didn’t happen overnight and the solutions are not going to happen overnight.

My company is called Healthy Motivation. It is talking about how we motivate people with the right kinds of incentives to move them into certain areas.

I refer you to the Small Business Administration. When you want a grant from the government in opening up a business and continuing a business, if you are from a diverse background, if you have a disability, if you are female, you are a triple whammy in my case, but there are extra points, if you will, that are given. Not to say that we should apply this kind of model to workforce issues and granting issues but to at least look at it and see how we might incentivize those kinds of areas.

The other piece is that the National Institute of Arthritis, Musculoskeletal and Skin Diseases--the fact that I can say that in one breath is actually pretty darn good--actually has for the last year-and-a-half, of which Lora and I sit on as members, along with many other individuals from throughout the country who represent very diverse populations, are helping NIAMS develop and improve their outreach of NIAMS related information to the diverse populations. This is a wonderful group of targeted--all five of the targeted diversity areas to ask these same groups to take a look at the study section issue, to take a look at the workforce issue in those particular institutes. We have expertise in those areas

and so it is a readily available group of experts who could be available to further their research in this area.

MS. NAUGHTON: Hi. Dr. Tabak, we are seeing progress. In my small state we have a minority woman heading up the Dental Society. The Medical Society has female minorities. They were entering the medical schools in the ‘90s. We had--Brown University had a woman president that made unprecedented steps in the biolife sciences and working with a public university. We have worked in the K-12 grades in the ‘90s. Those kids coming up that attend most likely the community college. We have worked with Brown and the University of Rhode Island and others as part of the state network to have those students that are showing promise in the science, including physics, be able to have access to the physics lab at Brown, et cetera. However, they need funding.

The Affordable Care Act has a provision that the states can elect to remove middle management in the Pell grants and in other programs. Much of that has not been actually effected. So that there would be more funding through that system but it’s also under pressure

from congress to not even exist.

So I think that again you have to reach out to U.S. Department of Ed and to the land grant colleges. That system includes the American Indian system as well. And work to see that that Pell grant stays stable and that there is some incentives for the states to utilize instead of having this management cost--put it more into having the students be able to go into the sciences. There could be fees for the science labs at the advanced schools. And also the labs mean less time for a job to help pay for the school.

So you--and they need to have the grades to go into the dental schools, the medical schools, et cetera. So you want to have them be able to show the promise of their intellectual and passions and not be diverted from just trying to have a subsistence living. So you have that complex but the Pell grant and utilizing that fund is one way that we could maybe make this really happen.

DR. TABAK: As a private citizen, of course, I can tell you my thoughts about Pell grants but as an NIH employee that’s not what--

MS. NAUGHTON: No. And, for instance, for students to apply for a Pell grant you need a Ph.D. they

are so complex. We have smart technologies that we could make available to help minorities be able to apply because they are most likely not going to be fulfilling that application.

MR. PAVAO: Dr. Tabak, our last question comes from Gardiner.

MS. LAPHAM: Thanks. This is clearly a compelling issue. Just one suggestion. NIH is not in this alone obviously. There are so many private foundations and organizations around the country that are funding young investigators and trying to get them in the pipeline for NIH funding. I would think if you all can play a leadership role in pulling these other organizations into this conversation and these strategies for how we can work through them as well to, you know, diversify their grantee pool.

DR. TABAK: We have and we are reaching out to organizations of that type. We're not in this alone. It has to be a partnership but the partnership has to be very broad.

DR. WASHINGTON: Okay. Now that we're done with the questions we're going to take a quick break.

If I could have the COPR members convene over

in this corner so we can do the group photo as well as photos with some of our retiring members, and let's start back up about five minutes after 3:00 to begin the COPR presentation for recommendations.

(Whereupon, a brief break was taken.)

RECOGNITION OF RETIRING MEMBERS

MR. PAVAO: Some of us are leaving, myself, Lora, Eileen and we had John Walsh, who could not be here today, out of the Alpha One Foundation--he actually had to travel to the Far East to do a presentation.

But I also wanted to take this time to recognize Jim Wong. He did come in as one of our cohorts and he did pass away from cancer. And he was a courageous public health warrior. He actually was very involved with the American Congenital Heart Defect Association and he was from California. So I just wanted to make sure at least we recognized Jim for all of his contributions to COPR but also that we're leaving with him in our hearts today.

With that said, we turn to Stephanie.

COPR PRESENTATION

MS. AARONSON: Thank you.

Thank you, Dr. Tabak. That was a great

overview earlier today and we very much appreciate the discussion on diversity.

(Slide.)

So the presentation that we put forward today is really a summary of the work we've been doing. Specifically, Dr. Collins had said that science education and obesity were real important to him. He really wants to dive deep into those two issues. So we spent yesterday with those two teams giving an overview of where they are, our feedback, discussion about next steps and how we might be more involved.

(Slide.)

That said, the Power Point was done this morning and it's not fair because your Power Point was very slick, had lots of picture, graphs. So if I just did this the whole time it might make our presentation better. I was looking at it and I was like it's so hard for me with a media background not to have images and video and comparing it to yours.

Anyway, get with the simplicity with which we go over our findings.

Also I wanted to--coming off your discussion a couple of themes that we--that resonate from each of the

presentations, each of the discussions that we had with the different teams at NIH. And the first four really relate to the issues of diversity that you were talking about in education and in trials.

They have to do with the translation of promotional materials and applications for diverse audiences and how uniquely different some of the different audiences are. It has to do with changes in outreach paradigms. Some many activities have been going on for a long time, traditional structures, resources are short, extending the resources of different communities, and we're kind of saying we just need to do more with less, and we can't. So I think we need--some of the things we need to kind of break away from the old paradigms of distribution and start thinking differently. It's not going to take a lot of work.

Engage rural communities and engage ethnically diverse organizations and diverse professional groups. Lora was great in listing those. And to attest to--obviously those organizations that Lora mentioned she has mentioned at every COPR meeting, in every meeting at every presentation, and again I think there's a rich resource that a lot of people at COPR can bring

connections to organizations that would help you reach the communities more efficiently than trying to go to them one by one directly.

And then just other--you know, some other big picture stuff is headlining your stories to all state groups and any time you talk, you know, what's the impact of the work NIH is doing. You gave a great presentation today and at the end you talked about the impact its having on the economy and the environment. You know, bring us in right away with the relevance. I think that's great and a lot of other presentations are not. Brand consistency and metrics. When you guys are setting out what you want to do think across all programs. We're seeing a lot of improve and increase but from what to what, what does it really look like. It's hard for us to give you feedback on communities if we're not shown point A to point B. So I just wanted you to think of those themes through it.

(Slide.)

So at the last meeting we did a pretty robust presentation on science education and how we might engage in that. We also began talking about new COPR communication tools. Yesterday we also in light of the

New York Times study we are working with John and his group to talk about ways that COPR could be supportive in brainstorming how to get in front of stories when we're looking at transparency and public trust and what that means for our group and how to help you all when you're hitting those conflict of interest issues that happen frequently.

(Slide.)

So for science education recommendations--am I going too fast? Okay. Previous recommendations have already been completed, which is great. There's obviously progress and we like to hear there's some contribution from COPR. Working across NIH, in preschool programs, engaging other children in the programs, and there are actually even high school kids who mentor middle kids, integrate curriculum with common core standards, and that is being looked at. And then we had also recommended last time and want to continue this recommendation--and, hopefully, we can move forward--incorporating a member of COPR into working groups and review boards across the--getting more engaged in science. And we encouraged last time more public and private partnerships around education, from industry to

Department of Education, National Science Foundation and CDC.

(Slide.)

And then some new recommendations.

So this--again thinking along the themes I mentioned before. Thinking about how the work you are doing is in the public interest and it's a showcase of how government is working. There is a great story to be told about this work, it’s impact in the economy, opportunities for careers, accomplishments to date, and then creating objectives that really are measurable and that help us tailor our input according to where you are and where you are trying to go.

Tony gave a great example of a map of where local programs are--local CIPA (ph) programs are and the overlap geographically with COPR members. And at our lunch and dinner last night we were talking about programs that we are engaged with that might match really well with some of the CIPA programs or encouraging people to apply for CIPA grants and maybe that would also feed into some of the diversity goals. And then again rural and Tribal communities raise again access is key and of course not limiting it to those two groups but those were

certainly raised as two groups that are not being met right now in terms of outreach.

(Slide.)

We can't do more with less. We talked about this. You know, buying less is costly and limiting. We have no money to buy lists for each teacher so let’s really think about how we’re spending that money differently because we’re just going to hit a wall. And we need new distribution methods for reaching more users so the money can be expanded and can go further.

There are a lot of additional influence of groups and these use the resources beyond teachers, local policy makers, health community agencies that want to use these resources that have been built for the classroom or to engage kids in their own groups.

Eileen was talking about an example where she has completely mined the website and found great resources to share with other people in her building, her and her community.

And then as you are looking forward let's think about the future of diverse work force. As you said, what does that look like for the needs in medicine and healthcare and what does it look like in terms of career

path, support and modules?

(Slide.)

I'm going to jump ahead to obesity. So then we also sat down with the Obesity Research Task Force. And as Amye (ph) mentioned in her remarks, I think the entire team is really excited about the work that’s underway. We've got a lot of people interested in this issue and a lot of people are already working on it. So we're looking forward to continuing dialogue at the biennial meetings as well as updates from the group on ways that we can contribute, including putting a representative of COPR on the working group task force.

We believe that the team is--the working group objectives should stay on target with the intervention of heavily populated areas, clearer metrics would help for moving from point A to point B in understanding where NIH can go with this, recognizing environmental and community factors is key.

And then looking at other organizations you want to gain--bring into the fold because there are so many people out there. I know you’re working with the Robert Wood Johnson Foundation, Kellogg, local community

groups, public health organizations are involved. There are more organizations at the community level that are heavily interested in this area and it could be an even more rich discussion.

There is also interest in news alerts about the research as it unfolds. It's a five-year research. There can be information coming out of it that people who are following this issue consider doing emerging science and education, which we call ENR, to community health professionals to find out how they can apply research that’s unfolding and news that’s unfolding in their daily practice. Again, the diversity of translation and materials is
key. And we look forward to continuing to work with this group.

(Slide.)

So those were two areas that we deep dove into according to Dr. Collins’ interest and I'm going to go back to public communications.

And this goes to our interests in increasing communications among COPR members, among OPLs with the Director's Office and something we put on our own agenda, and so we had a brainstorm with some of the OPLs this

week and we want to figure out how we can expand consistency in working with them, as well as some ideas that we have for different challenges they're having.

So one of the ideas is to make sure we have a liaison with each OPL. We have also offered to review some of the parameters around best practices in engagement for research. OPL--several OPL members have been great about reinforcing the need to have COPR members in NIH working groups and we hope that will continue. Two examples right now is Donna is part of the Clinical Trials website development and Lynn is part of the Down Syndrome Consortium. And those are examples of actually OPLs saying we should go get a COPR for public input as part of this working group.

And then we hope the OPLs will increase the participation at these meetings biennially so we can have a great exchange. Some of the things that we considered for them is morning electronic news briefs, helping them with the diversity of materials like Lora was saying in terms of speaking to diverse audiences and what that looks like, and using more common language and simplicity in materials and applications.

And then in terms of promotion--you know, we did talk about this. I think when you are dealing with stakeholder groups, you know, what's the headline, you want to give them about where all this work is leading. Making sure the communications is consistent across NIH for everything from social media to branding.

We had an example of a colleague who was at a conference where there was an exhibit space and there was probably 12 institutes exhibiting there all spread out and there was no common thread to know that these groups were from NIH and representing NIH. And what we're saying is it's really asking too much from the end user, especially when you go on line, to determine what’s the common thread here.

And then resource is transportable, especially in our digital age where everyone has their own Facebook page, newsletter, blog, twitter feed. Stories that are transportable, widgets, principles, downloads allow people to actually list stories and insert them into their own forums, blogs, newsletters, websites. And that might help actually brand some of the efforts you have as well as extend the information.

There is--we spoke a lot about what’s on the

web and that it would be great if NIH had a seal of approval on information that's emerging because if you go online you are often getting conflicting information whether the research is real or not real or status of it. So it's great if you see the NIH logo when there is new information and are really holding true to that.

In terms of outreach all the OPLs, stakeholder groups, professional organizations, state legislators, grantees, these are really engaged audiences. Use those as influencers to reach the larger public rather than trying direct to consumer. It will ease the drain on the staff, the cost, because there’s a lot of groups that we can engage. And again the rural community outreach is key. Greg has done a lot of work in that group and feels it would be very responsive to clinical trials given how their response was in other scenarios.

(Slide.)

In conclusion, it would be like me to change the power point presentation in the middle of it.

Okay, so our next steps. I had mentioned that

we would like to be more engaged with CIPA in the Office of Science Education and their working groups and review boards. We'd like to have a COPR member more engaged in the Obesity task force as well as continuing to engage with them on a biennial basis. And if we could identify a role for COPR in the HHS plan on multiple chronic conditions. I understand NIH has a portion for that. We'll be integrating more COPR members into OPL activities and recaps and reports. We have a liaison there.

As a working group we'd like to implement a progress report in terms of what was asked of us, what our contribution was, what really is actually more information so there is more a tracking of give-and-take between NIH and COPR. And we've actually implemented monthly calls, thanks to Sharia, and I think we'll start outlining specific
issues with subject area experts across NIH so we're getting really robust updates between the annual meetings so we come in with a lot more information and previous dialogue.

Communications for the Director's Office is working with the OPLs and stakeholder engagement

planning. So that is something that is big on our agenda next. And we'd also like to offer guidance on new ways NIH can get more public feedback on a regular basis from a larger group of public. That would be great.

And I just want to add based on Dr. Tabak's comments today that the interest in diversity is something we can add to our plate and consider a really robust kind of discussion with your leads on that issue to start drilling down and reaching specific communities, what that locks like, putting metrics against it and making sure we're actually seeing some results.

Thank you.

Any questions?

DISCUSSION

DR. TABAK: Did anybody else have other things to add because I know this is a group effort. No?

Okay.

So the common theme--and I know you were trying to make a pun but things went by a little quick but the common theme appeared to be communication which is not surprising. So if you could just rewind a little bit and

elaborate on the science education piece. So as you--so where you do see the key tipping point here for where COPR is uniquely positioned to help us make a difference? Is it overlap, the fact that you engaged at the community level or maybe if you could just elaborate a little bit on that.

MS. AARONSON: I think that some of the--the recommendations are kind of overarching based on our experiences working with communities and what that looks like and when we've had similar experiences trying to reach into various communities. I think from the expertise of the group they are dealing with a pretty diverse population at their level and they are in the field on the ground understanding how people learn, how they want to be engaged.

And I'm just going to go back to Lora's again because it is great. In terms of how to speak to different communities, if you want them engaged in a science, you think of you've got the different stages of life, you've got your Pre-K, you've got K-12, you've got the post graduate degrees, you've got post mom career changes and potentials, you could have people at different stages and you've got the extra layer of

diversity. And you've got people who are either engaged in trying to have one issue communicated in their community to different communities that might learn lessons from or you've got someone who represents very strongly a specific community who can tell you exactly how to speak to them at the different levels. So I think that will provide a lot of the richness when you are looking at the materials.

DR. TABAK: So that helps.

MR. NYCZ: One of the things I want to do when I get home is talk to the people who do after school programs or out-of-school programs. They're less structured than the school and have the people that we really want to turn on. They are from lower income families generally, you know, and there is a whole network of out-of-school programs nationally. So I don't know to what extent this is all plugged in but I'm going to approach our folks and if they go, wow, they didn't realize all these resources are out there, then you want them to talk to their national organizations or statewide organizations.

DR. TABAK: And the other part which I confess to being a Neanderthal about are social media. So you

went through a whole host of social media. Only a small fraction of which I even know what those things were.

MS. AARONSON: (Not at microphone.)

DR. TABAK: Well, you mentioned a whole--I mean I--I kind of know what twitter is because John has been desperately trying to teach me but they are a whole other bunch of things that I have no idea what you were even talking about.

MS. AARONSON: How much time do I have?

(Laughter.)

So obviously technology--everyone can create their own newsroom. I mean you certainly recognize that even a twitter response--something can go viral. Everything is a wire story now. You've got mom having her own blog, you've got so and so teacher having a listserv that they created, and maybe New Mexico or a certain community, you know, people are trying to use technology to make it faster and easier to communicate in the middle of the night whenever they have time.

So as you are creating materials it is hard to remember there is different levels for each person but it's going to be hard to get people to do extra work on behalf of NIH to share their story but you give them

content for what they're already
creating it makes it easier to spread the word and tell stories. So consider each of these things pieces of contents that are flexible enough to meet different technology expertise and levels.

(Simultaneous discussion.)

MS. AARONSON: Of course. So some people have a newsletter or a blog. Some people only tweet, like Sharia.

MR. PAVAO: Eileen has something to say.

MS. NAUGHTON: Yes. I have something. What we did trying to get into using social media with health access and messaging is the HIV site developed a widget which had a zip code connection.
And we were able to have that widget and then promote that widget via all kinds of means and L’Oreal is a huge international supporter for HIV education and they have hairdressers all across the United States. So they promised that they were going to pick this up and make this available to
all their clientele across the country. And L'Oreal as a partner also brought their teachers. They have educators in the hair sciences and they brought them to New York

and they did a huge promotion on HIV and how to get people to understand about getting a baseline screening, et cetera.

So the widget served as an easy test for people to plug in their zip code and know where the resources were proximate to them to get scientific, medical, you know, social assistance.

DR. BURKLOW: We have used widgets for everything from H1NI to peanut butter scares and sometimes we call them badges and widgets.

(Laughter.)

DR. BURKLOW: I may even make up a name and act like it's a real one and see if you buy it.

(Laughter.)

DR. : Which is what I thought you were doing with widgets but I said fine, excellent.

MS. APPELL: Just as another utility for content pieces, in my community everybody is legally blind. So it's easier for me to take a piece of content from the NIH very branded by the NIH and send it to my people who can zoom text it and do what they want, rather than disseminate a news letter to them. So the piece in social

networking is extremely important.

DR. TABAK: I just want to mention one thing as you are talking about all these things that I know so little about. This past--this week, earlier in the week, I was fortunate to speak to a group of people who won the NLM competition for apps. So you all know what this stuff is, right?

What do I know? Anyway--so on their website--on the NLM website you find the description of these apps and some of them might be very useful at the community level.

So, for example, one is this powerful search engine that pulls health data from everywhere. It was remarkable. I mean I saw this demo. It was remarkable and also based on zip code and so forth. So--and this is all free and you can download it or do whatever you want with it. So you might want to check that.

MR. PAVAO: I think we have no other comments. Questions?

DR. : (Not at microphone.)

DR. BURKLOW: We don’t have any public comments at this time? Oh, yes, we do. Okay.

Would you like to go to the microphone?

MS. DUPREE: Okay. This is just a comment. I'm Erica Dupree. I'm a student at the UDC David A. Clarke School of Law in D.C. I am currently in the administrative law class and part of our assignment was to come out to a government agency and come to one of their hearings, and here I am. And it was very interesting that this group was discussing diversity among minorities in the sciences.

I actually wanted to, I guess, share my experience with that because as an undergrad I was in biology and philosophy, and I had a few students who were--oh, I went to Swarthmore College during undergrad and there were a few of us who were in science, African-American students in the sciences. I have a best friend right now who is in medical school, and I remember varying experiences in the sciences at Swarthmore and I guess I just wanted to point out some of the issues that I experienced, which I think went along the lines of income and preparation through high school.

So just seeing students who came from low-income backgrounds having a bit of a harder time in the

sciences and I know at Swarthmore there were different departments. Our biology department had a great reputation for being supportive in general, which wasn't the case for the other departments which played a role in that. And for some of the Students--I also have a friend who is Native American, and for her things were difficult but she actually pressed through--she actually stayed another year to get her bachelor's in chemistry and now she's in medical school. But it was an extra year she put in. It was like deciding whether do I continue on this path or not for her.

So I guess all that to say when you're looking at how to bring more minorities into the sciences to consider issues like support and low-income backgrounds because those factors play out in such interesting ways.

For example, not seeing other students who had parents who were professors, you know, and were well-versed in academia and how that works versus students who didn't.

So thank you.

DR. BURKLOW: Thank you very much.

Donna?

MS. APPELL: I just want to say that we talked about people post graduate when you were speaking but certainly-and your comments were from the heart and lovely and I mean I thought about them deeply and it shows that the CIPA program is so important, that what Dr. Beck is doing is really, really important and we've got to really bring it down to young, young people. And I think that it's not going to be an instant fix but certainly that's where a lot of attention needs to go.

DR. TABAK: Your comments sort of underscore another little piece of the puzzle. So while we are seeing gains in the numbers of underrepresented minorities in professional schools, actually mostly medical school, dentistry is basically flat, the decision tree--do I go into a professional career, medicine, or do I go into a career in biomedical research?

The decision tree is very much skewed towards clinical endeavors. It's very, very much skewed towards going to medical school. And part of it, I'm reminded by Vivian Penn, because I asked her about this. I said what--you know.

She said, “Well, back in the ‘70s when we increased enrollment in schools of medicine around the country we specifically did so under the imprimatur of getting more people to go back to their communities to treat the underserved and that has stuck.

And so, so many individuals from underrepresented communities sort of have that as their focus. And again it's not a bad thing. It's a great thing but we'd like just to have a few of those people come into biomedical research. And for some of the reasons that you alluded to, financial. Do I go down the academic pathway where I may or may not be funded, where I may or may not get tenure or do I become a physician where obviously the opportunities might be a little bit more stable? So we have that little piece of the puzzle also that we need to deal with.

DR. OLSON: I just have to add you made all good points. I just have to say though so we know--I know in pediatrics and I think it's similar across medicine over the last 20 years there has barely been any increase in underrepresented minorities. And then there

is all these decision trees as you say and then there's the decision when you have finished your primary care training do you go to subspecialty work, and that's often where the clinician scientists are. And we do see probably fewer minorities then taking that path. So it's all so complicated and important.

MR. PAVAO: How much time do we do have? I just want to do a quick time check.

DR. WASHINGTON: We have until 3:45.

MR. PAVAO: 3:45. Okay.

Eileen?

MS. NAUGHTON: Just to emphasize as much as possible that the CIPA working with K-12 isn't really a waste of time. These kids take what they learn immediately and use it. They use it among their parents at the grocery store. So all of your emphasis in working with obesity and all of the these things and exercise and choice are really impacted by the K-12. So kids do not wait. They use it.

MR. NYCZ: And I just wanted to suggest a long term strategy to try to get at that point and that is the investment, for instance, in a dental PDRN and other kind of practice management stuff, if we

look for bridging between bench researchers and clinical researchers in the field and then we mix in a little--students in that mix, some of them will get turned on to the bench research. It's a way of reaching out in the communities to get people from those communities engaged even if the first ones go out in clinical. If they then tie in back with the academic health science centers and they get turned on by that, throwing some students in the mix may help generate more.

DR. WOOLEY: I also want to suggest a program that I was involved in as an undergraduate. I actually had an undergraduate grant to do research. It was funded by NSF. It was a long time ago. And I actually worked for two summers and the year in between during college in a research lab. And there is a difference between--I mean an internship, which is a short time sort of one-project kind of thing, and actually the experience of working through a grant, and I don't think that--the undergraduate research grant I really haven't seen in a long time those opportunities. It doesn't cost a lot and it might pay off benefits particularly if you were

targeted to the minority serving institutions.

DR. TABAK: These are ideas that many suggest. Part of it relates to what are the boundaries of the NIH mission? And some would argue you shouldn't have any boundaries. Okay. And that--but then others would say, look, finite resources, you have got to make a choice someplace. And so we are always trying to strike this balance. And I have to say again I absolutely understand the benefit of elementary education and exposing young kids to science and math but relative to other agencies we do so very little of this--again because of the way our mission is crafted--and so one of the things NIH has to come to grips is, you know, should we expand it or shouldn’t we expand it?

You know, how do we be more strategic in it and so forth? Or is there--so, for example, some people have argued--you know, NSF and Department of Education and other organizations are really dealing with K-12. Why don’t you all begin--if you’re going to work down the pipeline, why don’t you start thinking about community colleges which now for so many, many low income

individuals is the only option. I mean there are no other options except for the local community college where tuition tends to be somewhat reasonable.

And we actually have on campus a community college summer program now which--and I met with those young people last summer. They were amazing. Okay. They are just a tremendous group of kids.

So it’s a question of where do you pick your intervention but this is all interesting to factor into the equation.

I see hand signals here.

MS. NAUGHTON: Thank you. I'm squeezing in here but I wanted to bring up some other models from non-traditional sources. NASCAR, the pit was responsible for a lot of innovations in the OR and also team approach to healthcare. The other samples might be the--we just had an exciting baseball season, great, especially game six and seven. But those teams have farm leagues and they go all the way down into the kids. And they would not have the caliber of players that they have and the system they have but for the interconnections that are there. So what you are proposing to do and connect with other entities you shouldn't do alone. You should do in tandem

because it really has shown effectiveness in a whole host of other areas.

NEXT STEPS

DR. BURKLOW: Okay. With that, the next steps is Dr. Tabak will talk to Dr. Collins and report back and I'll join them as to all that has been discussed here.

Our next steps I think would be to schedule a call for December to talk about all the things that you have listed out here as far as the next steps and who is doing what. And then--

DR. TABAK: I want to formally thank the members whose term is now concluded. It's not a life sentence.

(Laughter.)

Carlos, Eileen, and Lora, and one individual who was not able to be here. We do thank you very much. We know that you are all very busy people and yet you have found the time and energy to help us in many ways, and we are really greatly appreciative. So thank you all.

DR. BURKLOW: And we don't have a gavel for you, Larry, but when everyone is finished, unless Stephanie or Carlos have other things to say, we'll

pretend you have a gavel and then you have to officially adjourn the meeting.

DR. : (Not at microphone.)

DR. BURKLOW: I know, yes. But, you know, budget cuts.

(Laughter.)

DR. TABAK: We’re adjourned.

(Whereupon, at 3:42 p.m., the proceedings were adjourned.)